



NATIONAL ACTION PLAN ON BREAST CANCER A Public/Private Partnership

W O R K I N G G R O U P

JANUARY 1999

THE CONSUMER INVOLVEMENT WORKING GROUP

The past several years have brought many changes in how health issues are addressed. Among these changes is the increasing involvement of those affected by a disease in the development of national programs and policies. However, consumers are not yet an integral part of many health planning efforts. Breast cancer consumers are defined as survivors of breast cancer, their families or significant others, and people at high risk of developing the disease. They represent an essential voice in the development, implementation, and communication of public health and service delivery programs, research studies, and outreach efforts related to breast cancer. Through their experience and expertise, consumers enrich the dialogue on research, prevention, and intervention efforts. The Consumer Involvement Working Group promotes appropriate involvement of individuals and representative groups of consumers in activities related to breast cancer, and it facilitates consumer representation for National Action Plan on Breast Cancer (NAPBC) activities and projects.

WHAT IS THE NAPBC?

The National Action Plan on Breast Cancer (NAPBC) was established in 1993 in response to a National Breast Cancer Coalition petition signed by 2.6 million people and presented to President Clinton. The petition called for a coordinated national strategy to combat breast cancer, the second leading cause of cancer deaths among American women.

The mission of the NAPBC is to stimulate rapid progress in eradicating breast cancer. The strategy for the Plan is to:

- *encourage new ideas and define unaddressed breast cancer priority areas.*
- *serve as a catalyst for national efforts to advance breast cancer knowledge, research, policy, and services.*
- *mobilize partnerships and coordinate actions among diverse public and private sector organizations and individuals.*

The work of the NAPBC is guided by a Steering Committee and Working Groups. The Steering Committee provides oversight for and ensures coordination across NAPBC initiatives. The Working Groups correspond to Plan priorities and identify, recommend, and oversee implementation of Plan activities. Plan implementation is coordinated by the U.S. Public Health Service's Office on Women's Health. Currently, there are five Working Groups. This fact sheet describes the Consumer Involvement Working Group.

CURRENT ACTIVITIES AND ACCOMPLISHMENTS

The Consumer Involvement Working Group is addressing the issue of adequate consumer representation by gathering information on consumer involvement in diverse organizations and programs. By conducting a Survey of Consumer Involvement, the Working Group seeks to identify gaps in consumer involvement and opportunities for closing those gaps. Because the level and nature of consumer involvement may vary greatly among different types of organizations, this survey has four related components: the Cancer Center Consumer Involvement Survey, the Breast Cancer Organization Consumer Involvement Survey, industry consumer involvement focus groups, and the Government Consumer Involvement Survey.

Cancer Center Consumer Involvement Survey

The Working Group is assessing the level of consumer involvement at cancer centers across the country. In collaboration with the National Alliance of Breast Cancer Organizations (NABCO) and the National Breast Cancer Coalition (NBCC), the Working Group developed a survey instrument to evaluate the nature and extent to which consumers are involved in the centers' research, clinical care, education, support, and outreach activities. Almost 200 cancer center representatives responded to the survey. The results, which are being summarized, will help the Working Group assess the current status of consumer involvement in cancer centers, explore ways in which consumer involvement facilitates or impedes the centers' operation, and identify opportunities for increased involvement.

WORKING GROUP ACCOMPLISHMENTS

Surveyed cancer centers across the country to assess consumer involvement in the centers' research, clinical care, education, support, and outreach activities.



Surveyed breast cancer organizations to determine their members' involvement with research institutions, health care providers, and policymaking bodies.



Developed a strategy to conduct focus groups to assess the nature and extent of consumer involvement in pharmaceutical and biotechnology companies and to identify opportunities for more effective involvement.

Breast Cancer Organization Consumer Involvement Survey

Also in collaboration with NABCO and NBCC, the Working Group surveyed a variety of breast cancer organizations about their members' involvement with research institutions, health care providers, and policymaking bodies (e.g., institutional review boards) whose activities affect consumers. In particular, the Working Group was interested in whether the organization members were involved in making decisions in these areas. The results from the nearly 200 responses to this survey are being summarized. In addition to helping the Working Group assess the current status of consumer involvement, this survey should help determine areas and methods for increased involvement.

The Working Group will synthesize the results of the cancer center and breast cancer organization surveys in a Survey Evaluation Report, which will include the surveys' data analyses, their findings, and implications for improving consumer involvement.

Industry Consumer Involvement Focus Groups

In collaboration with NABCO, the Working Group developed a strategy to conduct industry consumer involvement focus groups. Focus groups will be conducted with pharmaceutical and biotechnology companies to determine the nature and extent of consumer involvement in their organizations, explore how consumer involvement facilitates or impedes the companies' operations, and identify opportunities for effective consumer involvement.

FUTURE PLANS

Government Consumer Involvement Survey

The Working Group is developing the fourth component of the Survey of Consumer Involvement, a survey of consumer involvement in relevant Federal government agencies. The purpose of the Government Consumer Involvement Survey is to examine the contribution consumers make to the process of determining and implementing breast cancer-related priorities within government agencies. This survey will be disseminated in 1999.

FOR MORE INFORMATION

For more information about the Consumer Involvement Working Group and its activities, please contact:

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Other Survey Activities

The Consumer Involvement Working Group also will complete many of the other tasks related to the Survey of Consumer Involvement. It will finalize the Survey Evaluation Report and conduct the industry consumer involvement focus groups.

Liaison to Other NAPBC Working Groups

In addition, in an effort to facilitate consumer involvement across NAPBC activities, the Working Group will begin serving a liaison function. In this capacity, members of the Working Group will contribute their experience and expertise to appropriate projects initiated by the other NAPBC Working Groups.